
Citation:

Griffiths, A and Ashley, L and Kelley, R and Cowdell, F and Collinson, M and Mason, E and Farrin, A and Henry, A and Inman, H and Surr, C (2020) Decision-making in cancer care for people living with dementia. *Psycho-Oncology: journal of the psychological, social and behavioral dimensions of cancer*. ISSN 1057-9249 DOI: <https://doi.org/10.1002/pon.5448>

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Decision-making in cancer care for people living with dementia

Alys Wyn Griffiths¹  | Laura Ashley² | Rachael Kelley¹ | Fiona Cowdell³ |
Michelle Collinson⁴ | Ellen Mason⁴ | Amanda Farrin⁴ | Ann Henry^{5,6} |
Hayley Inman⁷ | Claire Surr¹

¹Centre for Dementia Research, School of Health & Community Studies, Leeds Beckett University, Leeds, UK

²School of Social Sciences, Leeds Beckett University, Leeds, UK

³Faculty of Health, Education and Life Sciences, Birmingham City University, Birmingham, UK

⁴Clinical Trials Research Unit, Institute of Clinical Trials Research, University of Leeds, Leeds, UK

⁵Clinical Oncology, Leeds Teaching Hospitals NHS Trust, Leeds, UK

⁶School of Medicine, University of Leeds, Leeds, UK

⁷Oncology Services, Bradford Teaching Hospitals NHS Foundation Trust, Bradford, UK

Correspondence

Alys Wyn Griffiths, CL521 Centre for Dementia Research, Leeds Beckett University, Portland Way, Leeds, LS1 3HE, UK.
Email: alys.griffiths@leedsbeckett.ac.uk

Abstract

Objective: Increasing numbers of people are expected to live with comorbid cancer and dementia. Cancer treatment decision-making for these individuals is complex, particularly for those lacking capacity, requiring support across the cancer care pathway. There is little research to inform practice in this area. This ethnographic study reports on the cancer decision-making experiences of people with cancer and dementia, their families, and healthcare staff.

Methods: Participant observations, informal conversations, semi-structured interviews, and medical note review, in two NHS trusts. Seventeen people with dementia and cancer, 22 relatives and 19 staff members participated.

Results: Decision-making raised complex *ethical dilemmas and challenges* and raised concerns for families and staff around whether correct decisions had been made. *Whose decision* it was and to what extent a person with dementia and cancer was able to make decisions was complex, requiring careful and ongoing consultation and close involvement of relatives. The potential impact dementia might have on treatment understanding and toleration required additional consideration by clinicians when *evaluating treatment options*.

Conclusions: Cancer treatment decision-making for people with dementia is challenging, should be an ongoing process and has emotional impacts for the individual, relatives, and staff. Longer, flexible, and additional appointments may be required to support decision-making by people with cancer and dementia. Evidence-based decision-making guidance on how dementia impacts cancer prognosis, treatment adherence and efficacy is required.

KEYWORDS

cognitive impairment, dementia, ethnography, older adults, treatment options

1 | INTRODUCTION

Increasing numbers of people are expected to live with comorbid cancer and dementia (CCD),¹ in a recent review estimates of the size of this

population varied widely, at up to 45% for some cancer groups.² Care of people with CCD may be more complex than other in populations.

People with dementia experience later cancer diagnosis, increased likelihood of treatment complications, and poorer survival

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rates.¹ They receive less treatment than those without dementia.¹⁻³ Individuals with dementia and their relatives may not disclose memory problems, and oncology clinicians may not ask about dementia,⁴ meaning the implications of dementia for cancer treatment may be poorly understood.

Decision-making in cancer care and treatment is complex, requiring factors including age and comorbidities to be balanced with patient preferences, and treatment and prognosis expectations.⁵ Many people with cancer experience decision-making uncertainty regarding treatment options, not fully understanding treatment intent or prognosis.⁵ However, comprehension and decision-making abilities may be further decreased in people with dementia.⁶

Few studies have specifically considered the role of decision-making in cancer care for people with dementia⁷ and their limitations include single site studies^{4,6,8} small-scale samples,^{6,8} inclusion of people with Mild Cognitive Impairment as well as dementia⁴ and only including staff perspectives.⁶ The studies to date identify the central role of families in decision-making,⁹ with people with dementia often depending on them to speak and make decisions on their behalf.^{5,8} Clinicians who support decision-making may have different priorities to the person with CCD, and their beliefs and understanding about dementia can impact advice given and the treatments offered, meaning people with CCD can experience a power imbalance and lack of autonomy around treatment decisions.⁶ Treatment decision-making for people with CCD is complex, particularly for those lacking capacity.⁸ Relatives are integral in supporting decision-making, but often have unmet information needs and feel excluded from the process.⁸ Reviews conclude decision-making in CCD remains under-researched,⁸ particularly regarding treatment goals in palliative and end-of-life decision-making.²

This paper explores cancer treatment decision-making in CCD as one theme identified within a larger UK study exploring cancer care experiences of people with CCD, their families, and healthcare staff.⁹

2 | METHODS

2.1 | Design

An ethnographic approach was taken, consisting of participant observations, informal conversations, semi-structured interviews, and medical note review.

2.2 | Setting

Oncology and associated departments in two National Health Service (NHS) Trusts in one UK region and their local communities.

2.3 | Procedure

Ethical approval was gained from the Bradford Leeds Research Ethics Committee [reference 243475].

In NHS Trusts, staff members (ie, nurse, consultant) identified and approached participants at post-diagnostic clinic appointment to establish interest in speaking to a researcher about the study. Study adverts were also shared with local community support groups and via social media.

Written informed consent was obtained for interviews and in-depth observations from all participants with capacity, with advice provided by a consultee for people lacking capacity.¹⁰ Ongoing consent was established prior to each observation.

2.4 | Participants

Participants were people with a diagnosis or suspected dementia (assessed via completion of the FAST¹¹) of any type, (mild to moderate severity), who were receiving/had recently received cancer treatment; relatives of people with CCD who had currently/previously received cancer treatment; and oncology staff with experience of supporting people with CCD. Purposive sampling was used to recruit a range of staff roles.

2.5 | Data collection

Researchers observed oncology appointments including consultations, treatment, and follow-up. Participants were typically met in reception areas to observe their entire hospital visit, during which informal conversations were also held, and documented within field notes. Semi-structured interviews focused on experiences of cancer care for people with CCD and were conducted in their home or a quiet hospital room. Interview topic guides were developed with the Lay Advisory Group. People with CCD and their relatives were interviewed individually, or as a dyad/group, depending on preference. Interviews were audio recorded and transcribed verbatim. Participants with CCD currently being treated at participating hospitals could opt to participate in an interview and/or observations. Medical notes were reviewed for any mention of dementia or associated issues. (See Appendix S1, 1 for more information on participants and procedure).

2.6 | Data analysis

Analysis was an iterative process exploring content and patterns in the data via triangulation across sources. Initial coding of interviews and observations was conducted independently by A.G., R.K., C.S. and F.C. Ethnographically informed thematic analysis¹² was used to develop a coding framework. This was discussed and refined with the wider research team, including lay members. Data collection and analysis ran concurrently, with early analysis informing subsequent data collection.

3 | RESULTS

Participant characteristics are summarized in Table 1. Observations and informal conversations (totaling 46 hours) were conducted with 12 people with CCD, 8 of whom also participated in interviews, and

TABLE 1 Participant demographics (N = 58)

	n (%)
Participants with CCD (n = 17)	
Female	10 (59)
Cancer type	
Lung	8 (47)
Prostate	4 (24)
Breast	1 (6)
Gastrointestinal	1 (6)
Other	3 (18)
Ethnicity	
White British	16 (94)
Hispanic	1 (6)
Age (M, range) (n = 13)	75 (45-88)
Relatives (n = 22)	
Female	14 (64)
Relationship to participant	
Child	12 (55)
Spouse	7 (32)
Sibling	2 (9)
Grandchild	1 (5)
Staff (n = 19)	
Female	14 (74)
Role	
Clinical nurse specialist	8 (42)
Radiographer	7 (37)
Consultant	2 (11)
Social worker	1 (5)
Patient transport officer	1 (5)

their families. We conducted 37 interviews (13 people with CCD, 18 relatives and 19 staff) lasting between 9 and 122 minutes due to varying communication abilities and participant preference.

Decision-making challenges were a major theme identified in the data. Not all study participants contributed data to each identified theme. Within decision-making three sub-themes were developed (please see Table 2 for an overview);

1. Ethical dilemmas and challenges
2. Whose decision?
3. Evaluating treatment options

3.1 | Ethical dilemmas and challenges

Decision-making raised complex ethical dilemmas, for example the potentially negative impact of people receiving their cancer diagnosis multiple times due to short-term memory loss. Staff and relatives experienced uncertainty and sometimes conflict over whether this upsetting process was the right thing to do. Thus, extended decision-making processes and support were required.

TABLE 2 Themes and sub-themes

Main theme	Sub theme
Ethical dilemmas and challenges were raised for families and staff members	Are we doing the right thing? —staff were concerned whether decisions were right
Whose decision? —balancing decision-making between different individuals was complex	Capacity and consent issues —perceptions of the challenges people with dementia faced in making treatment decisions
Evaluating treatment options presented difficulties balancing factors such as prognosis and managing side-effects	Balancing person's and family wishes —ensuring the person with dementia was included in decision-making was not always straightforward
	What is an option? —staff had to consider which options were appropriate for patients based on multiple factors
	Balancing and coping with impact of treatment —side effects, balancing quality and quantity of life, and impact on other conditions all had to be considered
	Considering the bigger picture —dementia, and the complications that this brings, was not always considered

You might have told somebody the diagnosis and then you have to tell them again and you tell them again and it's that thing of how fair is it to keep telling them? How fair is it then not to tell them? (L006, Lung Clinical Nurse Specialist [CNS])

Fluctuating awareness of their diagnosis sometimes meant people with CCD were less worried about cancer. For others, however, uncertainty about what was wrong caused anxiety.

I don't know what they are going to do with me, that's what I'm anxious about. ... I try not to worry about it, because it just upsets me so much. I don't like it. I don't know what's happening to my body ... I don't know what to do to make myself better and that's what frightened me. (L0035, man with dementia)

Ethical concerns arose when people became distressed receiving cancer treatment. Staff questioned whether they were doing the right thing, even though the person with dementia had consented and/or it was decided to be in their best interests.

It was very, very uncomfortable for all the staff because it's, "we shouldn't be doing this, because he's agitated. He's not liking it." So, it's supporting the staff, it's like, "well, if you want me to treat him, I will, because I've had the long conversation with him and he definitely

does want his treatment. He knows what he's letting himself in for" ... But that was a bit heart-wrenching for staff, because they're like, it's not right, we shouldn't be doing this. (L0042, Patient support practitioner)

Families sometimes perceived pressure to treat from clinicians and questioned whether their relative understood decision implications.

That was the big decision to say stop, we're not going to do anymore treatment. Even when he was in the hospice at the end of his life, they still wanted to tempt him back for radiotherapy to try and slow things down ... he said yes, because he didn't know what it was ... I had to say do you remember us going on the train and bus ... and then he said I can't go that far again. (C002, Wife)

In summary, decision-making raised ethically complex issues and doubts for families and clinicians around whether correct decisions had been made.

3.2 | Whose decision?

Responsibility for decision-making was also complex. Understanding and establishing whether a person with CCD had capacity to provide consent to cancer treatment concerned families and staff. Considerable time and effort could be spent trying to ascertain a person's understanding about treatment options and their implications. Where a person lacked capacity, staff typically took care to ensure decisions considered relatives' opinions and the implications of treatments.

You try and make sure that the whole team agrees this is in the patient's best interest and the patient will be discussed at a multidisciplinary team meeting and if there are issues of consent, they'll be discussed so the whole team can suggest alternative ways of dealing with things, or arrange additional meetings with the patient and family. (L0043, Consultant oncologist)

For relatives, decision-making responsibility was stressful and anxiety inducing, especially when views and decision-ownership conflicted.

I got really stressed with it, because I thought, everyone will want an input, because I've got family and they might push saying, well she should have the operation, but I'm the one who is the main career, that sees her nearly every day. They see her once a year. But suddenly everyone has got an opinion (L0011, daughter)

Family and staff generally prioritized inclusion of the person with CCD in decision-making processes. However, perspectives on the "right" decision did not always align and relatives' views were often

influential. When disagreements arose, staff or families sometimes questioned whether quality vs quantity of life was adequately considered when prioritizing treatment.

P1: I said I didn't want the treatment and they [family] more or less said yes you should ... I said alright I'll have it, but I said no to start with didn't I?

P2: I think it's not unfair to say that you're not processing the information that the Doctor told you and then we've to sit down about it and I asked you what you wanted to do and you said well you couldn't remember, so we had to go through it again. So, it's not a case of bullying or telling you what to do, but guiding you a little bit really. (L004-5, person with CCD and granddaughter)

Some relatives reported feeling excluded from decision-making, perceiving treatment was administered without their full understanding.

They imposed it. I wouldn't say I had no choice, but there were no enquiries or anything. It was a case of come back and we'll give her some treatment, then half way through, I found out it was radiotherapy. (L001, husband)

Other relatives saw clinicians as experts to take the lead on decisions from.

[Patient] says "With no disrespect, it's slightly going over my head anyway." [consultant] replies "You don't need to decide today" [patient] asks "How important is it, can it wait until after Christmas?" [granddaughter] says "I think if the specialists have looked at it and they recommend it needs doing we should take their advice, but it's up to you." (Fieldnotes L004-5, person with CCD and granddaughter)

Staff members shared families' uncertainties around optimal decision-making processes when people with CCD lacked decision-making capacity. They sought others' opinions where possible, offering multiple appointments and additional time to help families, and sometimes themselves, reach decisions.

She [daughter] would often say, I don't even know if mum really knows what we're doing here ... But there were a lot of consultations with her daughter before she got to surgery. (B007, Breast CNS)

In summary, decision-making required careful consideration of capacity issues and processes to ensure inclusion of sometimes varied perspectives of all involved and uphold the involvement of people with CCD.

3.3 | Evaluating treatment options

Interviewees reported a range of ways in which the additional needs of people with CCD were considered within treatment decision-making including the range of options available, their ability to cope with these and any resulting side-effects or longer-term impacts, and likely prognosis. "Fitness for treatment" was frequently discussed, with concerns here including how well people with dementia might tolerate anaesthetic, hormone treatment or chemotherapy. Decisions were more complex when cumulative treatments were possible.

...it's really difficult when people have memory problems ... if there's a choice as well, we might say, you can have local surgery. But if that shows that the disease runs up to the margins, we will need to go back and do more surgery and you will also have radiotherapy ... So, you may decide on the least invasive treatment, but it comes with the risk of more surgery ... with radiotherapy (B007, Breast CNS)

Typically, individual ability rather than a dementia diagnosis was prioritized in assessing treatment fitness, for example how well individuals would notice side-effects or tolerate specific treatment requirements.

Chemotherapy side effects can be life threatening ... it's too high risk, or they deem it that way, that if they can't report what's wrong with them, if they haven't got the ability to do that, then it would be too dangerous to give them the drugs (B006 Lung CNS)

Prognosis was another key consideration, given dementia is life-limiting and many patients were older and had other comorbidities.

Interviewer: Is there any reason you wouldn't give someone with dementia a certain treatment?

Participant: I we felt they were dying from the dementia. ... So, if they' requite late onset dementia, and they're more nursed in bed ... (B005 Lung CNS)

Where treatment would not significantly prolong life, decision-making focused on risk-benefit analysis in the context of dementia. For example, where people had no symptoms, pain or awareness of their cancer.

You don't want to put somebody at risk because if they're having palliative treatment ... chemotherapy for lung cancer potentially only adds three months to your life. They can be a very valuable three months, but if that can be shortened because you've done some harm... it's got to be that risk vs benefit argument. (B008 Lung CNS)

Some decisions were based around how the person might cope with the treatment consequences, rather than the treatment itself. For example, coping with being an inpatient post-surgery, vs the surgical procedure itself.

P2: We were frightened with the operation if she went on to a surgical ward ... I can just imagine you know ... "do you want any breakfast?" and it'd be "no," because she won't eat, "do you want a drink?," "no," we just had nightmares didn't we, thinking what's she going to do just laid there, how's she going to go to the toilet because she won't go up and go. (B014, daughter)

In other cases, decisions were determined not on physical treatment experiences or consequences, but by potential after effects on memory problems or the potentially traumatic treatment impacts.

If they've had for instance, a breast removed, they may have forgotten why that's been done. They may feel that they've been mutilated against their will or wishes. So, you've got to take that into account when you're choosing what treatments are in the patient's best interests. (L0041, Consultant Surgeon)

Whilst many staff actively considered the person's dementia during decision-making, a minority of families felt their relative's dementia and the "bigger picture" of potential treatment impact on their life, was not adequately accounted for.

They discuss hormone therapy, and that it can lead to memory problems. [Participant's] daughter sounds concerned at this ... a little bit more detail is given, but it is not clear to what extent this might be an issue. They are told that [participant] "needs" the treatment, as if it isn't an option, so the impact on his memory is not an issue for consideration, with the suggestion that they start it and see how he gets on (Field notes, L0039-40, man with CCD and daughter)

In contrast, when the "bigger picture" was considered, clinicians could recognize dementia-related concerns, such as the potential impacts of treatment on the person due to their dementia.

They were a bit scared of putting me [under anaesthetic] and then not knowing what my reaction was going to be when they're waking me up. Am I going to be confused? Am I going to get in to a state because I don't know where I am, what's happened. Then they said we'll make an appointment with an anaesthetist. He'll go through things with you and then we'll decide. (B009, man with CCD)

Although sometimes these important considerations were initially expressed by relatives.

Discussions at MDT suggested to assess suitability for surgery. I saw her today and it is her daughter's opinion, of which I agree, that it would be a huge upheaval to bring [participant] into hospital for breast surgery. (L0011, Medical Notes)

In contrast, on occasion staff had to manage families' expectations around treatments options.

We'd hoped that she might be able to cope with anaesthetic, but she couldn't. Then we looked at giving drug therapies and she wasn't receptive to those either. So, we've had to manage expectations for her daughter as well, around palliative treatments. (B008, Breast CNS)

In summary, dementia did not necessarily reduce treatment options, but was considered on an individual basis within the broader context of comorbidity, frailty, abilities, impact and prognosis.

4 | DISCUSSION

While cancer treatment in older adults often involves ethical dilemmas and complex decision-making,¹³ this study provides unique insights into the additional ethical challenges comorbid dementia adds and the variety of ways clinicians adapt their practice to try and support inclusive decision-making.

It was clear decision-making needed to be an ongoing process and when a decision had been made on treatment, this could be reassessed multiple times depending on the person's ongoing medical and personal response to the treatment. Additionally, there were specific ethical dilemmas such as the need for continual re-disclosure of a cancer diagnosis due to short-term memory problems. Research on diagnosis disclosures in dementia¹⁴ and cancer¹⁵ highlights the need for full, sensitive disclosure. However, little research explores cancer diagnosis in the context of memory problems and the potential need for repeat disclosures. Ethical challenges led to "moral distress" for clinicians, an issue discussed widely in healthcare,¹⁶ and specifically in oncology literature,¹⁷ where the need for ethical guidelines to support decision making is highlighted. Given the current research paucity, practitioners are working with little evidence-based guidance to support clinical practice.

Challenges arose when assessing capacity to make informed treatment decisions in people with CCD. While patients with cancer at end of life may have reduced decision-making capacity,¹⁸ our study identified that comorbid dementia can affect decision-making capacity earlier in the cancer journey, which oncology staff may not be prepared or trained to deal with. Assessment of cognitive function is vital during decision-making and delivery of cancer care to older people,⁴

to ensure decisions made are fully informed, but does not routinely happen in practice.¹⁹ We found relatives were integral to treatment decision-making, supporting reiteration and explanation of key information and discussion of treatment options. Previous research has highlighted their important role in facilitating inclusion of the person with CCD in decision-making⁶ but has also indicated there may be deference to relatives in this process.^{4,8} Our study confirmed these findings and identified the considerable burden caused by reliance on families for decision-making. While family burden associated with caring for an older person with cancer is well-documented,²⁰⁻²² the impacts of decision-making have not been highlighted, and our work indicates this burden may be greater when someone has CCD.

Evaluating cancer treatment options was also made more complex by comorbid dementia. Whilst cognitive impairment is known to reduce treatment adherence,²³ in our study fitness for treatment, rather than cognitive impairment specifically, informed decisions. Where this "bigger picture" was considered - including the impact of a person's dementia on prognosis, treatment suitability, understanding of potentially cumulative treatment options and ability to identify and report side-effects- shared treatment decisions and plans were able to be made. Again, while cancer treatment decisions, particularly in older people, always require consideration of an array of complex issues,²⁴ dementia brought greater complexity and prognostic uncertainty. Geriatric evaluation can prove beneficial in supporting decision-making in older populations,²⁵ however, as these did not arise within the data we collected, it was unclear whether these routinely occurred in oncology settings.

4.1 | Study limitations

This study was conducted in one area of the UK, across two NHS Trusts. The experiences of people with CCD may vary between hospitals, with further research required to validate our results. Triangulation of data sources was not possible for all participants and we sometimes relied on retrospective reflections on decision-making experiences. Although subjectivity is inevitable within ethnographic research, we mitigated this by acknowledging our preconceptions before data collection began, data being collected by two authors, reflexive journal keeping, group data analysis, and synthesis of multiple data sources.²⁶

4.2 | Clinical implications

Our study has indicated the following implications for oncology practice for people with dementia:

- Treatment decision-making requires additional time and repeated re-evaluation; longer and/or additional appointments may be required to support this;
- Oncology clinicians may benefit from additional training and support in communication with, and assessment of, decision-making capacity in people with dementia;

- Families play an important role in treatment decision-making and may experience additional distress and burden when supporting a person with dementia through this. Consideration should be given to how their information and support needs can be met within oncology services;
- Oncology clinicians need to ensure they apply an individualized ability focused assessment, considering the "bigger picture" of how dementia may impact cancer treatment options and side-effects, alongside potential longer-term impacts.

5 | CONCLUSIONS

Cancer treatment decision-making for people with dementia is complex, challenging and fraught with uncertainties, and should be considered as an ongoing process with emotional impacts for the individual, relatives, and staff. Oncology clinicians are currently working with limited evidence-based guidance on how dementia impacts on treatment prognosis, adherence and efficacy. More research is required to provide a stronger evidence base for treating people with dementia in oncology services.

ACKNOWLEDGEMENTS

We would like to thank the study participants and participating NHS Trusts for giving their time and sharing their experiences with us. We would like to thank Amanda Proctor for her support with study design and our Lay Advisory Group - June Hennell, Maria Walsh, Liz Jones and Margaret Ogden for their valuable input throughout the study. This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0816-20015). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

Alys Wyn Griffiths: study design, data acquisition, analysis and interpretation and drafting the manuscript, Laura Ashley: study conception, design and drafting the manuscript, Rachael Kelley: study design, data acquisition, analysis and interpretation and critical revision of the manuscript, Fiona Cowdell: study design, data analysis and interpretation and critical revision of the manuscript, Michelle Collinson: study conception, design and critical revision of the manuscript, Ellen Mason: study design and critical revision of the manuscript, Amanda Farrin: study conception, design and critical revision of the manuscript, Ann Henry: study design and critical revision of the manuscript, Hayley Inman: data acquisition and critical revision of the manuscript, Claire Surr: study conception, design, data analysis and interpretation and drafting the manuscript. All authors have approved the final article.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Alys Wyn Griffiths  <https://orcid.org/0000-0001-9388-9168>

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

How to cite this article: Griffiths AW, Ashley L, Kelley R, et al. Decision-making in cancer care for people living with dementia. *Psycho-Oncology*. 2020;1–8. <https://doi.org/10.1002/pon.5448>